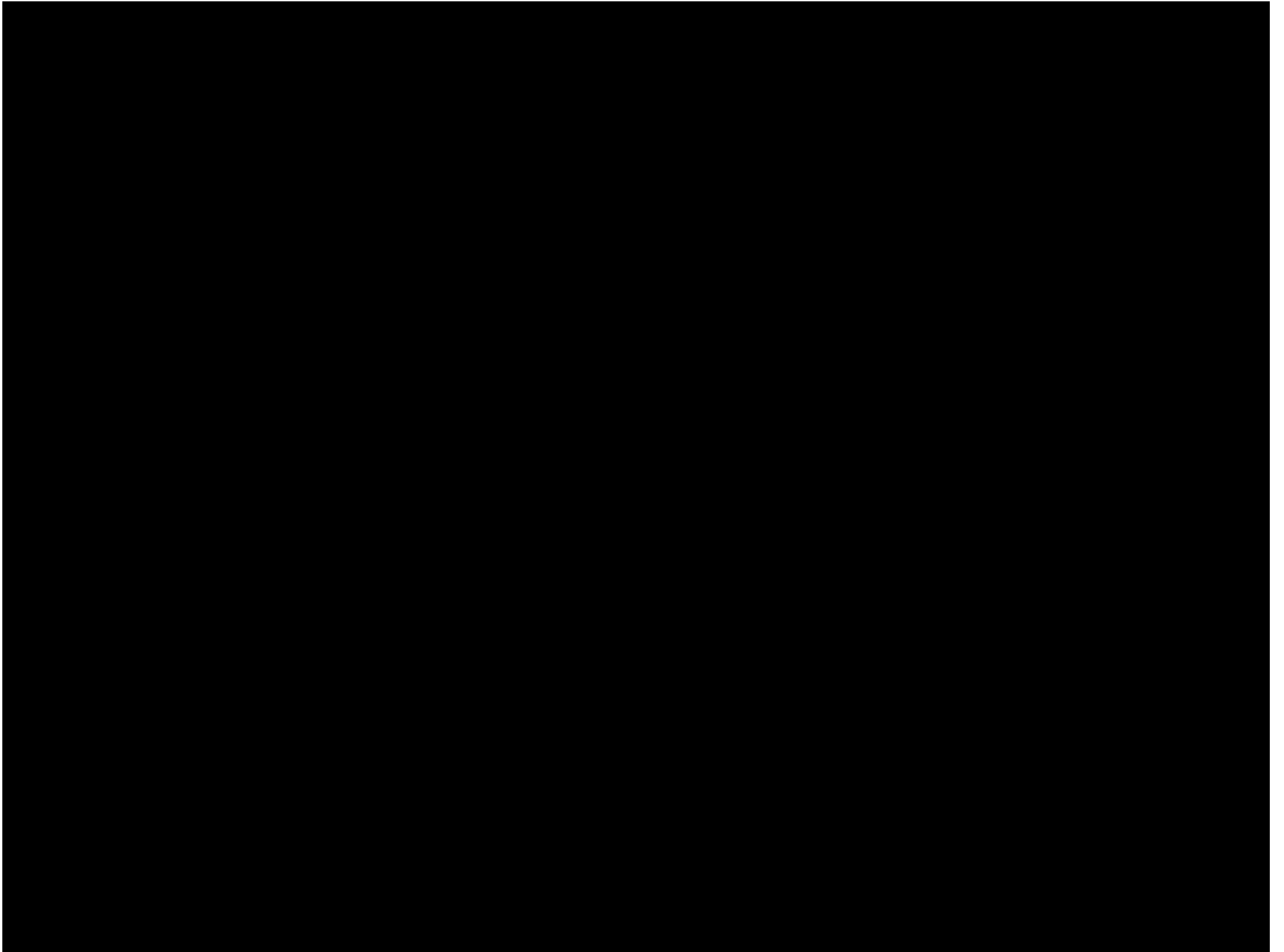

A Palliative Approach

Professor David Currow

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Flinders University

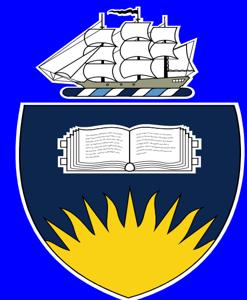
Adelaide

Australia

Rural Divisions of General Practice.
Adelaide. September, 2004.

A Palliative Approach

WHO 2002 definition of palliative care '… impeccable assessment … timely involvement…'

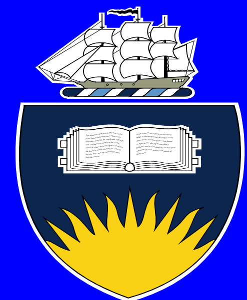


A Palliative Approach

- Breadth of Palliative Care

- A Palliative Approach

- Skilling people for the role



A Palliative Approach

PEOPLE HAVE BEEN DYING FOR A LONG TIME

A) DYING BADLY

B) CHANGING DISEASE

C) SOCIAL NETWORKS CHANGING

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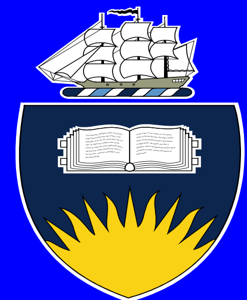
People have been dying for a long time

Why the need for ‘palliative care’?
- Community’s view of death, dying and suffering
- Community expectations around quality of care
- Changing patterns of illness and life expectancy
- Information explosion and the need for a more coordinated response

A Palliative Approach

Assess the physical, emotional, social, spiritual, sexual and financial context of what is happening for this person

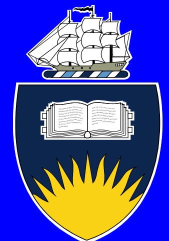


A Palliative Approach

134 000 Australians will die this year

Approximately half will be expected deaths

One third of these people will access care beyond their primary clinical carers



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256 specialised palliative services will see >24 000 people this year in Australia.

Average time from referral to death - 3 months

Median time from referral to death - 9 weeks

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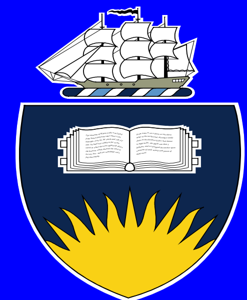
Palliative care is:

- optimising level of function
- optimising level of comfort

in the face of a life-limiting illness



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Palliative care

- not just the elderly
- not just cancer
- not just terminal care
- not just for the person with a life-limiting illness
- not just nice people (We die as we live)

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Palliative care

The needs of people at the end of life are very similar irrespective of the underlying life-limiting illness

Luddington Pall Med 2001

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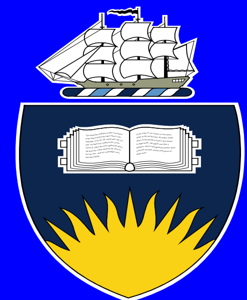
Who is the palliative care team?

The patient
Their caregivers
Their primary health professionals
+/- Specialist support



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Is there an assumption that good palliation is simple and uncomplicated?

Just commonsense?

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How do we maximise the quality and responsiveness of care for this person with a life-limiting illness and their carers?

How do we refine the care offered to *this* person?

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If we are to fully support patients and families in life limiting illnesses, what is it that they themselves define as their needs?

Cross sectional random national survey – USA (one confirmatory cross-cultural study)

Steinhauser et al 2000

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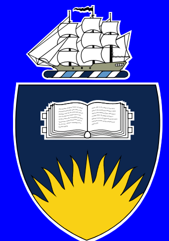
Asked

Patients

Family members (>6/12 after death)

Doctors

Nurses and other professional carers



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Surprisingly reproducible list among all four groups

- Pain and symptom management
- Preparation for death
- Sense of completion
- Being involved in decision making
- Being treated as a whole person

A Palliative Approach

For patients, important issues not emphasized by the other groups

- Having funeral arrangements in place
- Not being a burden
- Coming to peace with God

A Palliative Approach

For patients, important issues not emphasized by the other groups

- Helping others (creating meaning at a time of change, loss and suffering?)
- Maintaining a sense of humour (We are at any time in life the sum of all the issues that makes us the people we are)

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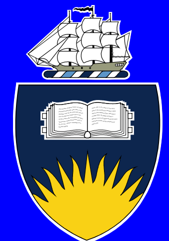
Magnitude of caring in Australia

Contributing AU$19.3bn to the economy for the care of family, friends & neighbours

6% are caring for people with cancer

(equal to 50% of all funded social services)



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Impact of carer burden

Physical well being fair or poor - 46%

Directly affected physical health - 59%

A Palliative Approach

Impact of carer burden

Mental and social well being - 34% report social isolation

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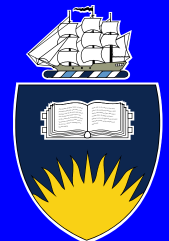
Impact of carer burden

Working

Working fewer hours -	29%
Give up job -	17%
Unpaid leave -	22%
Less responsibility -	16%
Refusing promotion -	13%



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Qualitatively, carers reflect a spectrum including:

- an unprecedented opportunity for growth

through to

- resenting the whole process and being overwhelmed by it.

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What do palliative services deliver?

A Palliative Approach

What do palliative services deliver?

(RCTs, Hearn & Higginson, Pall med 1998)

- Increased time spent at home / less time in hospital
- Carer and client satisfaction
- Improved symptom control
- Reduction in overall cost *to the health system*
- Increased likelihood of dying in place of choice

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What impact do palliative services have on carers?

Strong association with decreased mortality at in the first 18 months after death of spouse from an ‘expected’ death

Christakis Soc Sci Med 2003

A Palliative Approach

What impact do palliative services have on carers?

Strong association with 'moving on' for primary hands on caregivers

Abernethy 2004

Carer's Ability to Move On

(Carers who know whether a PCS was used)

Likelihood of being able to move on with life

100
90
80
70
60
50

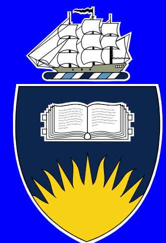
81
84
85
89
63
74
80
90

p=0.030
p=0.182
p=0.468
p=0.974

0-6 months
7-12 months
13-24 months
25-36 months

Months since death

PCS Yes
PCS No



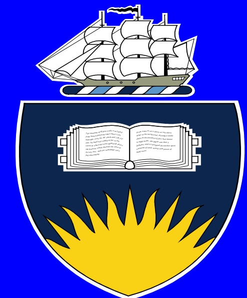
PCS influence on ability to move on is predominantly in the first 2 years

A Palliative Approach

- Breadth of Palliative Care

- A Palliative Approach

- Skilling people for the role



A Palliative Approach

Need to distinguish between:

- A palliative approach

- Interdisciplinary specialised palliative care

Field D, Addington-Hall J 1999 Soc Sci Med, Field BMJ 1995

A Palliative Approach

Needs *and strengths*-
based service provision

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A palliative approach

- what we bring as:
  - humans
  - health professionals
  - our specific discipline

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A palliative approach

All health professionals whose substantive work is *not* end-of-life care

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A palliative approach

In general practice, there will be on average 3-5 ‘expected’ deaths per year

Higginson Pall Med 1999

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Outcome measures for the:

- Individual

- The people around them

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Teams and Palliative Care

- We have identified complex needs

- No one person can meet these complex needs

- This is also personally challenging practice

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Teams and Palliative Care

The LONGER we have clinically known someone, the LESS likely they are to share with us the problems they face at the end of life

Christakis and Lamont 2000

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Teams and Palliative Care

There is a team for every patient. If you see 1000 palliative patients per year, you must generate 1000 teams to provide the necessary complex support.

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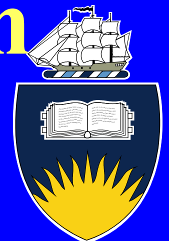
At the end of the day

a team approach is crucial

outcomes need to be measured for patients and their care network

co-ordination and new eyes can make an enormous difference



Ceasing Anti-cancer Treatment - Focusing on Comfort

I do my own palliative care -

new eyes

honest broker

no secondary gain / loss

The A-M, Hak T, Koeter G, van der Wal G. 'Collusion in doctor-patient communication about imminent death: an ethnographic study.' BMJ 2000;321:1376-1381.

A Palliative Approach

Consider 4 groups of people

A - people who utilise and benefit from a service

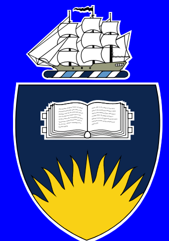
B - people who don’t utilise a service but would benefit from it

C - people who utilise a service but do not benefit from it

D - people who don’t utilise a service and would not benefit from it

A Palliative Approach

		Utilise	
		+	-
Benefit	+	++	+-
	-	-+	--



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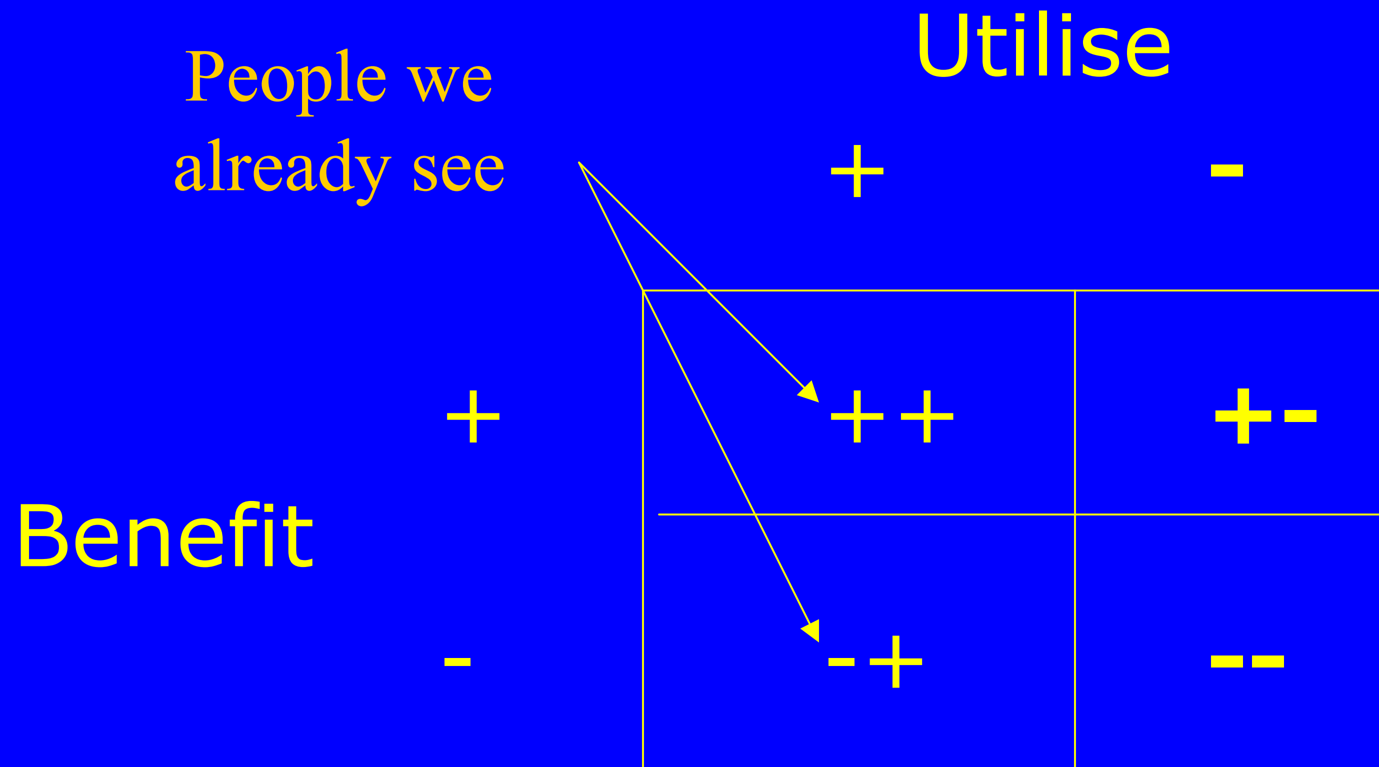

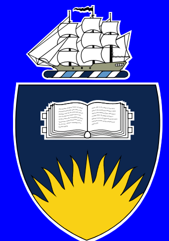

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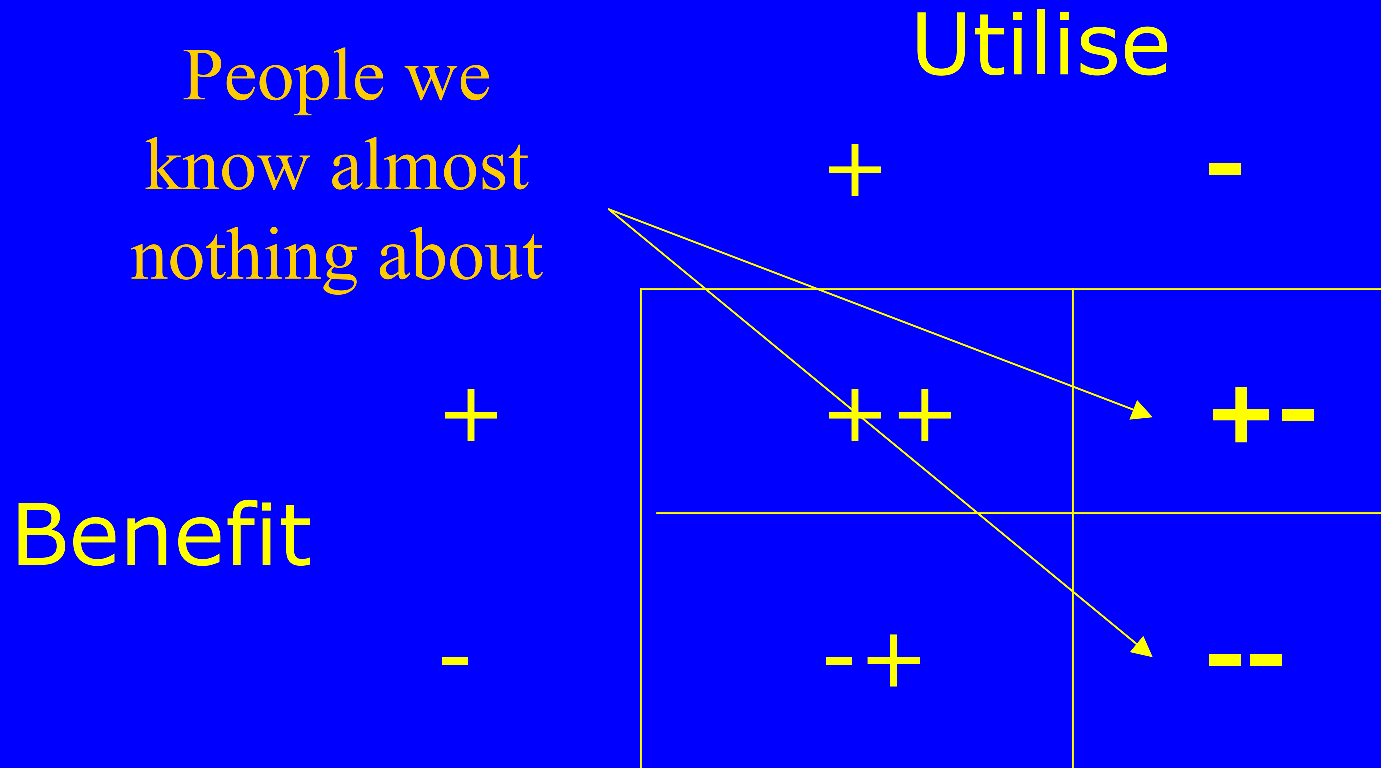

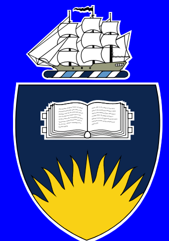

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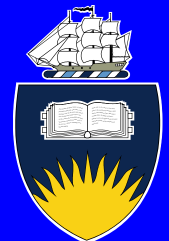
Need to move resources from...

		Utilise +	Utilise -
Benefit	+	++	+-
Benefit	-	-+	--



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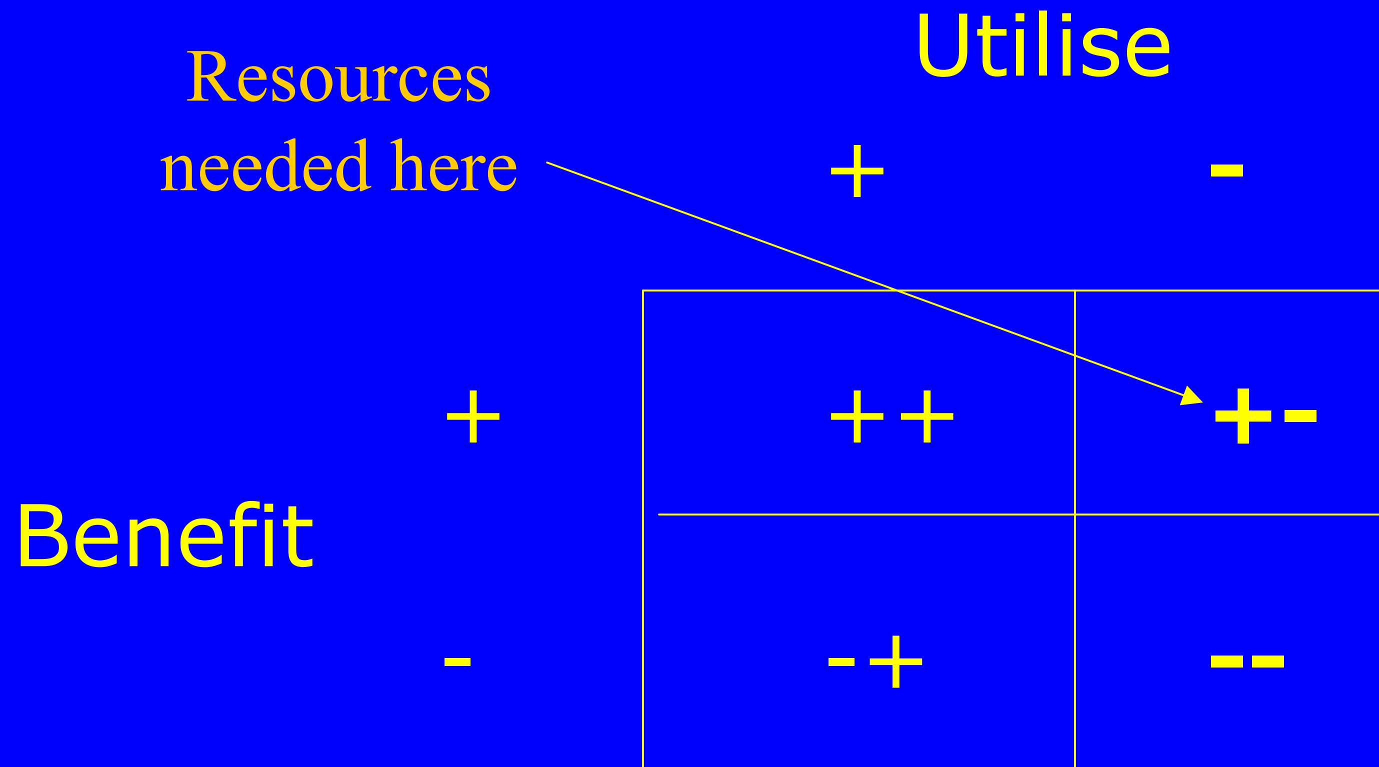
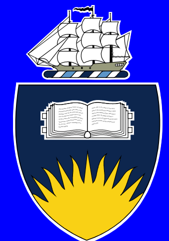
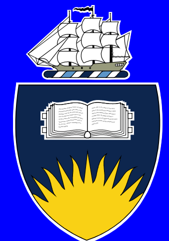




A Palliative Approach

very complex needs	Primary Care
complex needs	
needs greater than a palliative approach	
palliative approach (primary care)	



A Palliative Approach

- Breadth of Palliative Care

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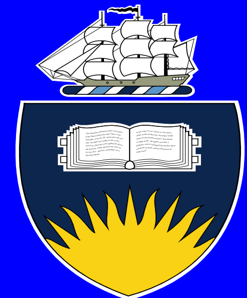
- Skilling up people for the role



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Two Groups – all health professional disciplines

Those in established practice

Those entering practice

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Key Issues for a competent palliative approach

National Palliative Care Curriculum development

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Key Issues for a competent palliative approach

Competency-based approach

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Key Issues for a competent palliative approach

- Communication
- Respect and appreciation
- Assessment and management
- Reflection

Similar to EAPC, AAHPC conclusions

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Key Issues for a competent palliative approach Communication

It is not innate

It can always be improved

It can be sustainably improved for existing practitioners

Maguire BMJ 1994

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Key Issues for a competent palliative approach Communication

Key areas that people will not volunteer

Finances, realtionships, self image / sexulity, fears, hallucinations

Maguire BMJ 1994

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Key Issues for a competent palliative approach

Respect and appreciation

The diversity of responses to life-limiting illnesses and the baggage we bring to the end of life. (We die the way we live)

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Key Issues for a competent palliative approach

Assessment and management

- Ongoing

- Complexity of life-limiting illness and comorbid medical conditions

- the assessment of all aspects of this person in the context of their life and illness

A Palliative Approach

Key Issues for a competent palliative approach

Reflection on:-

our practice (professional)

Ourselves (personal)

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Conclusions

- Major health needs
- Outcomes beyond the person dying
- Skills for established and training clinicians